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ABSTRACT

Steps are outlined in the construction of two self-report assessment scales designed to measure general life satisfaction and leisure activity levels of developmentally disabled adults. The potential usefulness of a reliable, valid self-report instrument as a measurement tool in client programming is noted in the context of a review of similar existing scales for older nonhandicapped as well as developmentally disabled persons. The scale developed to measure life satisfaction used a 5-item multiple-choice format (happy-face-to-sad-face). Responses to the activity scale incorporated a frequency measure, and negatively as well as positively worded questions were included to minimize response bias. Each scale was administered to approximately 120 developmentally disabled clients (ages 50-85) and to knowledgeable informants (e.g., resident manager or day program supervisor). Among reported results were the following: (1) perceived health was significantly correlated with life satisfaction; (2) clients rated their own life satisfaction more highly than did informants; (3) there was a close correlation between clients' self-reported activity levels and informants' perceptions. Elements of the two scales requiring further testing and refinement are discussed. Thirty-seven references are provided. (JW)

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STANDARDIZED ASSESSMENT OF THE DEVELOPMENTALLY DISABLED PERSON

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The history of life satisfaction, morale and activity scales in the gerontological literature is extensive. There is a large body of over 30 years of research and a myriad of instruments which have been developed and utilized in this area. Before I discuss the instruments which were developed for persons with developmental disabilities I would like to discuss the traditional scales used with non-handicapped population and their background.

Over 35 years ago the University of Chicago, Department of Sociology, began extensive studies into the "well being" of older Americans. People such as Cummins, Henry, Bernice Neugarden, & Robert Havinghurst tried to determine by use of subjective life satisfaction scales what factors (e.g. sex, housing, marital satisfaction) influenced "well being".

The first study in this area was conducted by Cavan and his colleagues (1949). It focused on measurement of what was termed "personal adjustment" in old age.

While numerous gerontological survey studies include an instrument designed to measure life satisfaction, there are few (Taylor, 1977; Roson, 1977; Nydegger, 1977), theoretical papers defining or delimiting the concept. The emphasis of research in this area is empirical and implied, focusing mainly on problem solving and program development. Therefore, the scales themselves are diverse and interpret the concept based, often on the practicality of the research at hand.

Many researchers have defined life satisfaction as a multidimensional concept. The most commonly used measure: Life Satisfaction Index of Neugarten, Havinghurst & Tobin (1961). They divided this concept into five components: zest (as opposed to apathy), resolution and fortitude, congruence between desired and achieved goals, positive self-concept, and mood tone. Their questions reflected the hypothesis that these components

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were positively related "well being." They believed that for a person to be content, they should enjoy every day activities, view their life as being meaningful, believe they have basically achieved their life goals, feel positive about themselves and remain optimistic with essentially little depression. The reliability measure (Kuder-Richardson-20) was .79 (Wood, Wylie & Sheafor, 1969). Validity measures between the life satisfaction index and independent ratings by clinical psychologists were .39. Correlations with other instruments indicating subjective well being ranged between .38 and .88 (Neugarten, Havinghurst & Tobin, 1961).

Another multidimensional scale is the Philadelphia Geriatric Center Morale Scale (Lawton, 1972) which defines high morale as not only satisfied with oneself but also that there is a environmental niche for the subject and an acceptance of life. The internal consistency of the instrument (determined by Kuder-Richardson 20) was 81. Test-retest comparisons found variance in the reliability of subscales from .22 to .81 with a total reliability of .75.

Validity correlations comparing this scale to Q sort evaluations by raters who were familiar with the subjects were .43. Correlations between the Philadelphia Geriatric Center Scale and other subjective instruments range from .37 to .79 (Lohmann, 1977)

A third prominent multidimensional scale is the Bradburn Affect Balance Scale (Bradburn, 1969). Bradburn divided this concept of personal well-being into 2 operational definitions. There are (1) positive affects, and (2) lack of negative affects which can demonstrate a high satisfaction. Questions focus on perceptions about everyday life situations (e.g. during the past week did you ever feel very lonely or remote from other people).

Test-retest reliabilities ranged from .76 for affect balance to .83 for positive affect. Q values for 3 days of repeat testing were between .86 & .96. Internal consistency (as shown by Crombach's alpha) were .66 for positive affect and .70 for negative affect.

The correlations of the Bradburn with single-item indicators of satisfaction were approximately .33.

Other scales are based on a some-theoretical hypotheses that subjective well being is an unitary and unidimentional concept. The Kutner Morale Scale defined morale as "a continuum of responses to life and

living problems that reflects the presence or absence of satisfaction, optimism and expanding life perspectives (Kutner, Fanshel; Togo & Langner, 1956). This scale was developed to measure personal adjustment and then to examine variables which affect it. The test-retest reliability was quite high (.90%). No independent informant rating validity has been conducted. Correlations between this measure and other subjective pencil and pen tests range from .39 to .88 (Lohmann, 1977).

There are a number of scales which include one single global item designed to gauge life satisfaction or happiness. These include:

Rose (1955) "In general how satisfied are you with life?"

Duir's (1974) "Taken altogether, how would you say things are these days. Would you say that you are very happy, pretty happy or not too happy?"

The Cantril Ladder (Cantril, 1965) asks the subject to place him/herself on a ladder with ranges from 0 to 10.

All of the above measures rely exclusively on the subjective perception of the subject - no collaboration by an informant is solicited. These are essentially self surveys - as Larson (1978) concludes the responses are "quick assessments given in a social situation." As such they do not reveal a deep psychological factor. Rather, they are affective perceptions of every day living - a sort of social verbal description.

Studies utiliaing these instruments in gerontological research have found many independent variables to be associated with life satisfaction scales. Perceived health measures are the strongest predictors of life satisfaction scores. One of the most typical measures of health is a ranked question. "In general, would you say your health is very good, good, fair, poor or very poor?" The correlations between these self perceived health measures and the life satisfaction scales range from .2 to .5. (Edwards & Klemmack), 1973; Palmore & Luikart, 1972); Spreitzer & Snyder, 1974). However, correlations comparing physicians' ratings of health to well being measure have been low, but significant (Cutler, 1973; Edwards & Klemmack, 1973).

Other factors influencing life satisfaction scales significantly include, (1) lower socio-economic status (Louis Harris, 1975), (2) being married or never married (Larson, 1978), (3) having transportation

available (Cutler, 1975) and (4) having adequate or improved housing (Lawton & Cohen, 1974).

The development of activity scales followed closely behind that of the life satisfaction scales (Bull, 1980). The first and main theory of the University of Chicago which focused on personal adjustment in old age was entitled the Disengagement Theory by Cummins & Henry (1960). Its basic tenet held that as one ages, the more one withdraws from society voluntarily, the higher their personal adjustment and life satisfaction will be.

Against this theory was a school that felt that activity was the important ingredient in determining satisfaction. As one ages, the more activities that are engaged in, the more social interaction one participates in, the higher will be the life satisfaction and adjustment. Thus, a large number of activity scales were developed to test these hypotheses.

Bull (1980) classified activity scales under five main categories:
(1) Multidimensional Measures of Leisure:

One of the best examples of this is the Leisure Activities Scale by Havinghurst (1957). Here the respondent select two of his favorite leisure activities and answers questions on many dimensions of this activity. The meaning of the leisure consists of 12 statements from which the respondent picks three statements that are most applicable to his two activities. He then rates his performance in their activities from apathetic and bored to well known among associates for the competence in a particular leisure activity. Reliability between two rates has not been particularly high for the entire scale (mean of .56%). However, Havinghurst (1957b) reported a Spearman-Brown reliability coefficient for the social role measure of from .86 to .95. This assessment was actually conducted within the context of a two hour interview which also probed for other facets of the respondent's life.

The second category of assessment instruments in the activity realm were termed General Leisure Inventories. Here a number of activities were listed and the respondent checked which activities he/she participated in.

Often a measure of frequency was included in the scale - participated in the activity last week, last month, last year. Second categorization of the time period would be participated "a lot", "some, but not a lot",

"hardly any at all", "not sure". An example of this is the Leisure Participation Scale of the National Council on Aging (1975). No reliability or validity studies have been done on most of the scales of this type.

The third classification of leisure time focuses on the history of leisure activities in the older person. An example of this is The Free Time Activities Scale developed by Peterson, Phelps and Longino (1976) for a study which explored living in a retirement village. Here a list of possible activities is read to the subject which responds whether he/she participated in the activity prior to the age of 50 and now. Interview questions probe changes in activities.

The use of the mass media has played a large role in the lives of Americans both young and old. Several scales have been developed to assess the effect of television on the activity behavior of individuals. The Communication Activity Scale of Graney & Graney (1974) illustrates this type of instrument. Questions probe the amount of television watched per day and the number of other social activities engaged in (such as visiting friends and neighbors, telephoning, going to church or other civic groups).

There are only two scales which actually attempt to assess the activity level and satisfaction of the participant in the activity. The first of these, the Elderly Leisure Attitude Scale (Teaff, Ernest and Ernst, 1975), categorizes types of activities (e.g. activities emphasizing mental endeavors such as studying taking adult education courses; or activities involving producing efforts, such as certain hobbies like woodworking, leather tooling, sewing, etc. It then asks the respondent to rate society's position regarding these activities. It probes into how guilty the subject would feel about having a "life of leisure" and finally asks that one which best matches how the subject spends his leisure be selected (from My leisure time is always filled with thousands of things I want to do... to I always feel quite bored during my leisure time.)

The second scale, Leisure Activities and Satisfaction, cited in Bull (1980) asks some multiple choice questions about how satisfied you are with your favorite activity. It categories activities into those that concern the family, those concerning work, leisure or community. This

scale has never been published. Neither of these two scales have any information regarding reliability or validity studies.

Bull (1980) points out a number of criticisms with these existing scales.

First, most of them are listings of activities and fail to measure frequency. Someone may garden twice a year - for someone else gardening may be a daily preoccupation. Square dancing for one participant occurs weekly and for another four times a year. How to measure frequency - Bull (1980) suggests two possibilities: (1) frequency during a specific period of time (e.g. number of times/month), or (2) time within a specific time frame (e.g. number of minutes/day).

Second, the place where the activities occur should be specified - is it a solitary activity or were other people involved? Categories could be created: coin collecting and French cooking are both hobbies. This classification system could prove useful in comparative studies.

Lastly, there are few reliability or validity studies on any of the scales. Test-retest assessments should be conducted as should comparisons between subject and informant ratings.

When we first began looking into this area of subjective assessment of persons with developmental disabilities, we came across an article by Paul Cameron (1984) an associate professor of human development at St. Mary's College of Maryland. We had attempted to measure what he termed "happiness" in three populations: (1) physically handicapped individuals with muscular diseases, paralysis, missing limbs, blind or deaf, (2) aged as compared to young adults and middle aged persons, and (3) retarded children. He found no differences between physically handicapped and non-handicapped persons. He also found oldsters as happy as younger adults. However, when he developed his research strategy with the retarded children, he stated "because we thought it would be difficult to gather accurate self-report data from retarded children, we compiled reports from trained observers and questionnaire responses of parents and teacher" (p. 64). Observers rated retarded boys as happier than their nonhandicapped peers both in the classroom and playground. No differences were observed between retarded and normal girls in either environment. While teachers reported normal children as better adjusted, they felt the retarded children were happier.

As in a number of other studies, this research did not ask the developmental disabled subject how he or she felt. The assumption is that this population is incapable of providing accurate, reliable information with how they feel. Very little is known about their feelings or perceptions of their well-being or their environment. The reliability and validity of the information they report has been virtually unknown (Sigelman, et al, 1979).

There have recently been several studies which have used subjective report from clients about heir feelings as a measurement tool. (Pennhurst study, 1984; Kazdin, Matson & Senatore, 1983; Matson, Kazdin & Senatore, 1984; Reiss & Benson, 1985). The Pennhurst study attempted to compare the well being of clients who were deinstitutionalized into the community with those who remained at Pennhurst. In light of the significance of their research the investigators wanted to include measures which represented perceptions of these residents. They noted several problems they encountered: (1) Representativeness of the sample is limited since nonverbal severely retarded clients could not respond to the questionnaire; (2) Did their responses reflect their consistent perceptions? and (3) Response bias or the tendency for a subject to answer all the questions in the same manner.

While no remedy was devised to correct the first problem, these researchers developed an instrument to measure consumer satisfaction which took into account the possibility of inconsistent or incomprehensible responses. Four of the questions had a matching question posed in a different manner for example, do you like the people who work here? had as its counterpart "which face is most like how you feel about the staff? Questions were designed in four formats:

a) Yes - no

b) Either - or

c) Open - ended

d) Multiple choice with 5 face drawings (from a big smile to a big frown)

For clients who had consistent responses (similar answers to alternately posed questions) the "movers" became more satisfied with their living arrangements and staff but were slightly more dissatisfied with their day program. The reverse was found with those who remained at

Pennhurst. They were significantly dissatisfied with their living arrangements, but more satisfied with day programming.

An instrument designed to detect psychopathology was developed by Matson, Razdin & Senatore (1984), The Psychopathology Instrument for Mentally Retarded Adults. For the self-report form subject is asked each question. He or she then responds with a Yes or No response. There is also an informant form. Both internal consistency measures (coefficient alphas and Sperrman Brown formulas) for both informant and self-report formats were high (.65 to .88). Informant forms exhibited moderate to high test-retest correlations.

The correlations between this subscale and the Hamilton Rating Scale for Depression on the informant forms were high (.74). The self report form was correlated with the Beck (.33). Two informant ratings were moderately but significantly correlated with this depression subscale - the Hamilton Rating Scale for Depression (.20) and the informant version of the Total Psychopathology Scale (.16). There is an interesting feature in the Zung Depression Test as modified for this population. A series of pre-questions are given to determine if the client understands the nature of these questions before the commencement of the actual test.

Against this backdrop the UMKC-UAF began to develop self report assessment instruments for a federally funded project which had two components (1) the training of case managers in issues important in their work with older clients; and (2) the enhancing of the social support network by pairing older clients with non-handicapped peers. We wanted to develop an assessment tool which would hopefully be capable of reflecting difference in their general satisfaction and activity level.

For the satisfaction scale we decided to select the multiple choice - happy face to sad face format. The original principal investigator on this project, Jim Intagliata with Barry Willer, had conducted a study on deinstitutionalized mentally ill clients in an attempt to ascertain the quality of their life in the community. They had used a 7 point likert-type scale for responses. Since many of this population was low functioning, they were asked to point to one of seven faces which reflected how they felt. Since we felt the level of understanding among these older clients was perhaps even lower, we decreased the response selection to five.

We also elected to utilize the pre-test questions similar to those of the adapted Zung test. These were:

a) How do you feel when you go to a party and have a good time?

b) How would you feel if you lost a good friend?

c) What do you like to eat best? How would you feel if you had lots of _____(name of food they like to eat)?

d) How would you feel if you fell down and broke your leg?

In order to "pass" the pretest, the client had to comprehend 3 of the 5 questions. Nine items were selected for the final form of this quality of life assessment.

1. How happy are you about the friends you have?
2. How happy are you about the people you live with?
3. How happy are you about what you do in your free time? (When you are not working)
4. How happy are you about what you do during the day?
5. How happy are you about the time you are away from where you live? (Like eating out, going to movies or ball games)
6. How happy are you about the amount of money you have to spend?
7. How happy are you about (name of main program activity).
8. How happy are you about the place where you live?
9. When you think about yourself over the past few weeks, how do you feel?

Prior to each question, the respondent was requested to select the face which describes how he or she feels.

Taking into account the criticism of Bull (1980) that a frequency measure should be included in any assessment of activity, a different response categories were selected for this scale:

none of the time
some of the time
lots of the time
all the time

These correspond to the categories employed in the adapted Zung depression scale. Before each question however subjects were instructed to answer if they did the activity. However, we wanted to first know if the older subject understood the context of the question.

The activity scale had a series of pretest questions to determine if the client comprehended the meaning of the questions. Negative questions as well as positively worded ones were included to minimize response bias. These questions were:

a) Do you want people to be nice to you?

b) Do you like money?

c) Should other people hurt you?

d) Do you like to eat rotten food?

e) Does it snow in the summer?

f) Do you like to have fun?

The actual test questions included:

1. Do you visit with other people where you live?
2. Do you plan games with other people?
3. Do you spend time in your room by yourself?
4. Do you visit with people who do not live in your building?
5. Do you go to stores and shops?
6. Do you talk to people?
7. Do you telephone friends?
8. Do you go out to eat with other people?
9. Are you bored, that is, do you feel like there is nothing interesting to do or nothing that you want to do?
10. Do you go out and do things with other people, like go to movies?
11. Do friends call you on the telephone?
12. Do you visit with relatives?
13. Do you like to be by yourself?
14. Do you take small trips to places like parks, zoos or ball games?
15. What did you do yesterday?

Subjects for reliability of these scales were 155 persons with developmental disabilities aged 50 to 85 years. There were 70 males and 85 females in this sample. One hundred twenty nine of these clients were able to answer the pretest questions appropriately for the quality of life scale. However, an additional 10 clients did not complete the entire set of questions.

For the activity scale, thirty clients could not comprehend the pretest questions. An additional two subjects did not complete all

questions. Thus, these statistics are based on 123 subjects.

Informants were requested to complete similar forms for satisfaction and activities. Informants were persons determined to be the most knowledgeable about the client-residential managers, sheltered workshop or day program supervisors.

The means for the client and informant forms of the life satisfaction scale are found on Table 1. Clients perceived their satisfaction higher than did informants. The total scale scores of clients and informants were significantly correlated at the .01 level (.1108). Thirty percent of the individual items were also correlated.

Table 2 delineates the item-total score correlations. All items were significantly correlated with the whole scale score. The reliability as reflected by Crombach's alpha was .828 for the client version and .9080 for the informant form.

Table 3 lists the means for each question for the client and informant forms. The means for these two versions were quite close. Note especially question 1 - visits with other people where he or she lives - 2.63 vs. 2.56. Question 11 is also quite close - goes out and does things with other people vs. going to movies 1.95 for clients' and 2.02 for informants. The total scale scores were also significantly correlated. The negatively worded questions were not correlated significantly. All of the items on the client version were highly correlated with the total score. However, 3 items on the informant form were not correlated with the total score. Again, these were the negatively worded questions. The Crombach's alpha coefficient for the client version was .73 and .62 for the informant form.

The activity scale and the life satisfaction of the client version were significantly intercorrelated with a Pearson of .303, significant at the .003 level. An initial attempt has been made to correlate the results of these scales with other demographic data that we obtained from the subjects.

In many of the studies in the gerontological literature the perceived health status of the respondent was correlated with their life satisfaction score. Similarly, in this study the perceived health of the older client was significantly correlated with their life satisfaction score (Pearson of = .379, significant at less than .001 level).

Interestingly, as in the gerontological literature, the health status as perceived by an informant was not so correlated with their life satisfaction score (Pearson of .1384). The informant's perception of the client's health status was correlated with perception of the activity level of the client (.24). The subjective perception of health was not correlated with the client version of the activity scale ($r = -.052$).

We attempted a multiple regression to determine what variables were important in predicting the subjective life satisfaction of the older client. Three variables entered into the equation accounting for approximately 25% of the variance. These were how healthy they felt they were ($r^2 = .14$); the sex of the client (r^2 change = .05) and the subjective activity level of the client (which added .05 to the variance).

Discussion

Both of these scales - life satisfaction and activity, have shown some degree of reliability and validity during this preliminary testing. These results show a close correlation between the perceived activity level of clients and the collaboration of this by informants. It would appear that there are some questions which could, contrary to the early research in this area, be answered by clients themselves in a relatively consistent reliable manner.

There is still much work to be done on the standardization of these scales. Test-retest procedures within short intervals should be conducted. More investigation should be performed to determine if the negatively stated questions (e.g. are you bored) on the activity scale should be changed. Even on the informant form these were not correlated with the total scale score.

These assessment tools could be important in several circumstances. Self-advocacy is an important tenet in modern philosophical ethics in the care of mentally retarded persons. Many self advocacy organizations as People First, The Fifth Stand, & Project Two have been established with the purpose of permitting and promoting persons with development disabilities to advocate for themselves. As Herr (1983) aptly states "The self advocacy movement challenges the stereotyped view that others always have to speak for retarded people." (p.214) Each person should be allowed, to the best of their ability, to express how they feel. An attempt should be made to incorporate these subjective perceptions into programming plans. One mechanism to obtain this knowledge with a client is to be able to use reliable, valid, self-report instrument as a measurement tool.

As in the gerontological literature, it would be interesting, with a reliable and consistent scale to be able to ascertain satisfaction in diverse settings (e.g. institutional vs. community placed; day program vs. sheltered workshop. Satisfaction could be used as a dependent variable (what determines high life satisfaction) or independent variable (is high life satisfaction correlated with achievement or success in vocational program?)

It is hoped that measures as these two scales - life satisfaction and

activity will prove useful in enhancing the lives of these individuals with developmental disabilities.

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TABLE 1

Item Means for Clients and Informants with Correlations of Clients and Informants

		N=	Client (119)	Informant (136)	Correlation
1.	How happy are you about the friends you have		4.16	3.70	.0421
2.	How happy are you about the people you live with		4.07	3.07	.1052
3.	How happy are you about what you do in your free time?		3.87	2.89	.0344
4.	How happy are you about what you do during the day?		4.14	3.00	.1095
5.	How happy are you about the time you are away from where you live?		4.20	3.20	.0167
6.	How happy are you about the amount of money you have to spend?		3.76	2.65	.1981 **
7.	How happy are you about (name of main program activity)		4.31	2.87	.2292 **
8.	How happy are you about where you live?		4.02	3.09	.2996 ***
9.	When you think about yourself over the past few weeks, how do you feel?		3.54	2.96	.1144
	Total Scale Score Standard Deviation		36.93 (5.68)	25.86 (4.93)	.2208 **

TABLE 2

ITEM AND TOTAL SCORE CORRELATIONS OF THE CLIENT MOOD AND LIFE SATISFACTION PROFILE FOR DEVELOPMENTALLY DISABLED PERSONS

Scale	Item	Version Client	Informant
1.	How happy are you about friends you have?	.6776 ***	.6705 ***
2.	How happy are you about the people you live with?	.6587 ***	.8027 ***
3.	How happy are you with what you do in your free time (when you are not working)	.5299 ***	.7468 ***
4.	How happyare you about what you do during the day?	.6782 ***	.7743 ***
5.	How happy are you about the time you are away from where you live?	.6305 ***	.6699 ***
6.	How Happy are you about the amount of money you have to spend?	.7844 ***	.6786 ***
7.	How happy are you about (name of main program activity)	.6468 ***	.7495 ***
8.	How happy are you about where you live?	.7365 ***	.7763 ***
9.	When you think about yourself over the past few weeks how do you feel?	.5767 ***	.8051 ***
	alpha Crombach reliability	.8277	.9080

TABLE 3

MEAN SCORES OF ITEMS FOR THE CLIENT AND INFORMANT VERSIONS OF THE ACTIVITY SCALE WITH THEIR CORRELATIONS

Scale	Item	Version Client	Informant	Correlati
1.	Visits with other people where he/she lives	2.63	2.56	.2343 **
2.	Plays games with other people	1.87	2.01	.0979
3.	Stays in his/her room by himself/herself	1.98	1.92	.3250 ***
4.	Visits with people outside the residence	1.83	2.15	.1356
5.	Goes to stores to look or buy things	2.12	2.09	.3658 ***
6.	Has nothing to do	2.68	1.79	-.1093
7.	Talks to people	2.81	2.74	.0363
8.	Telephones people	1.66	1.44	.3192 ***
9.	Goes out to eat with otherpeople	1.92	2.00	.2940 ***
10.	Is bored	1.89	1.67	.0787
11.	Goes out and does things with other people like going to movies	1.95	2.02	.3476 ***
12.	Is called on telephone	1.64	1.46	.3466 ***
13.	Visits with relatives	1.82	1.78	.3109 ***
14.	Stays by himself/herself	1.92	1.77	.0900
15.	Takes small trips to places likes ballparks, parks, or zooes	1.89	2.03	.3053 ***
	Total	30.15	24.22	.1576 *
	(Standard Deviation)	6.33	4.18	

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